

# “Well, I Think There Is Great Variation...”: A Qualitative Study of Oncologists’ Experiences and Views Regarding Medical Criteria and Other Factors Relevant to Treatment Decisions in Advanced Cancer

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**Key Words.** Terminal care • Medical ethics • Decision making

## CME Learning Objectives

List non-medical factors that influence decisions about limiting treatment in advanced cancer.

Discuss the problems associated with value-based treatment recommendations.

Describe possible strategies for improved ethics and evidence-based treatment decision making in advanced cancer.

## ABSTRACT

**Background.** Surveys indicate considerable variation regarding the provision of cancer treatment at the end of life. The variation cannot be fully explained by differences concerning the clinical situation or patients’ preferences. The aim of this qualitative study was to explore medical oncologists’ experiences with advanced cancer, as well as their views of the relevance of medical and nonmedical criteria for decisions about limiting treatment.

**Methods.** Qualitative in-depth interviews were conducted with physicians working in medical oncology in tertiary care hospitals or district general hospitals in England. Purposive sampling and qualitative analysis were performed.

**Results.** Physicians reported that a number of nonmedical factors influence professional decisions about the offering or limiting of cancer treatment in advanced cancer in addition to medical criteria. Physicians’ individual judgments about

the benefit of treatment, as well as the amount of their clinical experience, were cited as such factors. In addition, the physicians’ perceptions of the patient’s age and life circumstances were reported to influence their treatment decisions. Multiprofessional team discussions and the systematic collection of relevant clinical data regarding the outcomes of different treatment approaches in advanced cancer were suggested as strategies to improve the quality of treatment decisions.

**Conclusion.** The findings of this study provide explanations for the variation in treatment in advanced cancer. Making value judgments explicit and gathering more appropriate clinical data on the outcomes of treatment near the end of life are prerequisites for improved ethical and evidence-based treatment decisions in advanced cancer. *The Oncologist* 2013;18:90–96

**Implications for Practice:** Survey research indicates that there is considerable variation concerning treatment at the end of life that cannot be explained by clinical features or patients’ individual preferences. This qualitative study adds to existing literature by providing information about physicians’ distinctions (i.e., “active treatment” versus “palliative care”) and related clinical as well as ethical implications in the context of care for patients with advanced cancer. In addition, the interviewed oncologists report a number of value-laden non-medical factors that are viewed as influential for decisions about the provision or limitation of cancer treatment against the background of often scarce evidence. The findings of this study suggest that, in clinical practice, multi-professional team discussions on value aspects of decision making and a systematic gathering and analysis of clinical data that can be applied to end-of-life practice may contribute to an improved evidence- and ethics-based treatment decision making in advanced cancer.

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## INTRODUCTION

Treatment decisions regarding patients with advanced cancer pose complex medical and ethical challenges [1–6]. Evidence indicates that there is an increasing aggressiveness concerning the application of cancer-specific treatment near the end of life [7]. At the same time, data indicate that more treatment is not necessarily associated with better health outcomes [8]. Moreover, the increasing costs of cancer treatment in the last phase of life pose a considerable challenge to the health care system [9–11].

Surveys have repeatedly shown considerable variation concerning the treatment of patients at the end of life [12–14]. Statistical analysis indicates that these variations cannot be explained by differences with regard to patients' preferences. Patients' age, available resources, and local practice patterns have been shown to be associated with decisions about the provision or limitation of cancer treatment at the end of life [13, 15]. Quantitative research shows that the clinician is one predictor regarding decisions about the continuation or limitation of cancer treatment at the end of life [5, 16]. Although the aforementioned quantitative data serves as an important indicator for a possibly inadequate provision of treatment at the end of life, the data on statistical associations have little explanatory function. Such research can neither inform about the underlying reasons for the variations observed nor provide insight into how they come into practice. One possible way to get a more detailed insight into these issues is to explore the experiences and views of those involved in treatment decision making and to try to make expert knowledge, which is often implicit, explicit. The appropriate methodical approach to answer such research questions is qualitative research.

To our knowledge, there is anecdotal evidence [17] but little systematic qualitative explorative research [2, 18] on clinicians' reasons for decisions about the continuation or limitation of cancer treatment at the end of life. Research into physicians' rationales with regard to treatment decision making in advanced cancer is important for several reasons. First of all, it contributes to a better understanding of the variations observed concerning end-of-life treatment. Secondly, qualitative explorative research can serve as a starting point for larger quantitative studies, which may confirm or reject the hypotheses generated by qualitative research regarding the variables relevant to treatment decision making in advanced cancer. Last but not least, empirical information about decision criteria and variable decisions can serve as a starting point for the development of policies and professional training regarding ethical decision making in advanced cancer.

In this study, we interviewed medical oncologists in England about their experiences and views regarding treatment decisions for patients with advanced cancer. This article focuses on the narratives of interviewees about medical criteria and nonmedical variables that may contribute to physicians' judgment about the provision or limitation of cancer treatment. The aim of this paper is to provide a better understanding of the underlying basis of physicians' decisions about whether to provide or limit cancer treatment in cases of advanced disease. The findings of the qualitative study will be discussed against the background of ethical principles, as well

as the available evidence relevant to treatment decisions for patients with advanced cancer.

## PARTICIPANTS AND METHODS

Physicians with a minimum of 3 years of clinical experience in medical oncology in the U.K. were included in this study. The sampling strategy consisted of an initial convenience sample of three interviewees. This was followed by an unselected sample of six members of the U.K. Association of Cancer Physicians. The final three study participants were selected according to characteristics possibly relevant for physicians' experiences and views (i.e., purposive sampling). Interviewees fulfilling these characteristics were approached with the support of interviewees who had already participated in the study (i.e., snowball technique). In accordance with the protocol agreed by the South West Multi-Centre Research Ethics Committee (ref. 06/MRE06/52), written informed consent had been elicited from all research participants prior to the research interviews.

### Face-to-Face Interviews

Semistructured interviews were conducted by the first author, a research fellow in medical ethics, and a qualified physician in internal medicine with 4 years of clinical experience in hematology and oncology. The topic list of the interview guide had been developed by the authors based on a literature review and on the results of a similar research project conducted with physicians in hematology and oncology in Germany [18, 19].

All interviews started with an open-ended question about a typical treatment decision in the context of care for patients with advanced cancer. The order of the topics and the emphasis with which these were discussed during the interviews depended on the respective interviewee. The term "cancer treatment" was not specified but, if not indicated otherwise, was used for chemotherapy and/or immunotherapy. The interviews varied in length between 27 and 73 minutes (average: 56 minutes). All but one interview was scheduled in the participant's workplace.

### Data Analysis

Interviews were audiotaped and ad verbatim transcripts and thematic qualitative analyses were conducted. The generation of new concepts and hypotheses that emerged as a result of the iterative process of data analysis and data interpretation were the central aims of the methodological approach. In this study, essential principles of qualitative analysis—namely the constant comparison of data, open coding, writing memos, and purposive sampling—were used to explore physicians' perceptions and views regarding treatment decision making in advanced cancer.

After the ad verbatim transcription of the audiotaped interviews and a check of data, all transcripts were analyzed and coded by the first author. The codes express the content of the data analyzed as understood and conceptualized by the researcher (open coding). As part of the iterative process of data gathering and data analysis and the process of constant comparison of data, similar concepts were merged into more abstract categories and major themes relevant to the research questions. In line with the approach to grounded theory as for-

warded by Strauss and Corbin, the development of themes was not purely inductive but also took place in light of already known concepts (e.g., central concepts of the ethical debate on end-of-life decision-making). These concepts were compared critically with the narratives and also used to stimulate the discussions with interviewees [20].

Quotes from the interviews were selected to illustrate the conceptualization of data and allocated to the concepts and categories that were derived from data. The enrollment of participants was stopped following the decision that the analysis of more interviews did not generate new codes or enrich existing categories (theoretical saturation). The qualitative analysis was performed with the help of the Atlas Ti 6.1.12 program (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany).

The authors are experienced researchers with more than a decade of practical expertise of qualitative research in the field of clinical ethics. In line with the expertise gathered in the meantime, the following measures were taken to enable an intersubjective understanding of the physicians’ narratives and to enhance the validity of the results:

1. A selection of transcripts were analyzed by two more researchers (S.S., P.B.) to ensure consensus regarding the general themes and categories identified as part of the analysis.
2. Preliminary analyses of data and respective parts of the original transcripts were presented to all authors and discussed in a series of the regular empirical ethics seminars at the Institute for Medical Ethics and History of Medicine, which are attended by researchers with expertise in different fields of medicine, medical ethics, and social sciences. Feedback of the seminar participants was used for the adjustment of the interview guide, as well as for the further data analysis of interview transcripts.
3. Findings of empirical and conceptual research on treatment decision making at the end of life were taken into account during the more advanced process of data gathering and analysis.

RESULTS

Interviews were conducted with 12 physicians working in medical oncology in National Health Service (NHS) hospitals in England. Four interviewees were women and eight interviewees were men. Table 1 summarizes the characteristics of interviewees and their workplaces.

As part of our analysis, we identified three central themes that are relevant to a better understanding of the physicians’ decision about the offering or limiting of cancer treatment in patients with advanced disease:

1. Distinctions between treatment approaches and their implications
2. Medical criteria and nonmedical factors relevant to treatment decisions in advanced cancer
3. Strategies of professional decision-making in situations of scarce evidence

Distinctions Between Treatment Approaches and Their Implications

The physicians were asked at the beginning of each interview to describe typical treatment decisions when caring for pa-

Table 1. Characteristics of interviewees (n = 12)

Characteristics	n of physicians
Gender	
Female	4
Male	8
Work experience	
3–5 yrs	2
6–15 yrs	4
>15 yrs	6
Rank	
Specialty trainee, yrs 1–3	1
Specialty trainee, yrs 4–7	2
Consultant	9
Workplace	
Cancer center/tertiary care hospital	8
District general hospital	4

tients with advanced cancer. In this context, the respondents distinguished approaches of active treatment from those of palliative care. Both labels covered a spectrum of treatment scenarios. The term *active treatment*, for example, was not limited to curative treatment but was also used for treatment that alters, at least interim, the natural course of the disease.

“I think if you’re describing active treatment, you’re describing something that is influencing the natural course of the disease.... Whereas I see palliative as . . . the primary aim is symptom control, it’s not disease control if you like, it’s symptom control.” (Interviewee 3)

“And if our goal is to cure or to give them a good remission or to improve the quality of life.... If they were at the end of the line, that was no active treatment; that was at best supportive care . . . then we would explain that to them.” (interviewee 11)

Our analysis suggests that the framing of a treatment approach as “active” or “palliative” has both clinically and ethically relevant implications concerning the focus of care and the perceived role in the decision-making process. With regard to the focus of care, interviewees describe the change from “active” to “palliative” as a shift away from a disease-oriented model towards the needs and preferences of the patient.

“If their disease has got to a point that we can’t kill the disease . . . we change from sort of treating the cancer to treating the patient.” (interviewee 6)

In terms of their role in the decision-making process, interviewees seem to switch from being an advocate for active treatment towards the role of a more neutral or even ambivalent counselor in situations of palliative care.

“If you knew you had a curative treatment . . . you go and say to the patient, ‘This is going to be really difficult, but we’re able to cure you and we’re going to get you through’ . . . In the true English fashion, jolly along

through it. And that's very different, I think, from a very palliative intent where there is a balance of . . . where you're ambivalent." (interviewee 12)

"I mean usually if somebody has got a 20% chance of benefit, I would try and persuade them to have the treatment . . . Once response rates start going much below 10%–15%, I am increasingly trying to persuade patients not to continue the treatment." (Interviewee 12)

### **Medical Criteria and Nonmedical Factors Relevant to Treatment Decisions in Advanced Cancer**

To understand the foundation underlying physicians' decisions about the offering or limiting of cancer treatment in individual cases of patients with advanced cancer, the possible variables were explored in depth. In this context, the physicians all mentioned "diagnosis," the "stage of disease," "patients' health status," and "available treatment" as the usual "medical and clinical decision criteria." However, interviewees also acknowledged that there is variation within the medical community with regard to these decisions.

"Well, I think there is great variation.... So there'll be a judgment needed of how serious is this patient's condition, a view that the physician has formed of what are the patient's wishes and desires, and [this] can get scrambled or can get misinterpreted." (interviewee 2)

As part of our further analysis, we identified two groups of so-called nonmedical factors possibly influencing the physicians' decisions about the offering or limiting of treatment in advanced cancer: physician factors relevant to treatment evaluation and physicians' perceptions of patients' age and life circumstances.

### **Physician Factors Relevant to Treatment Evaluation**

Interviewees indicated that physicians' values and priorities regarding the goals of treatment (i.e., increasing length of life vs. improving quality of life) are relevant factors for their decisions. These priorities were described partly as personal value judgments and partly as judgments influenced by physicians' professional background and ethos (e.g., years of professional experience, disciplinary background).

"Well, it depends... I think it depends on the oncologist's philosophy, doesn't it? My philosophy is if I'm giving something palliative, the most important thing is their quality of life.... Other people's philosophy is that they want to keep people alive for as long as possible and they will carry on treating them till the patient dies." (Interviewee 11)

"Younger medical oncologists, particularly who wish to put most of their patients into trials, who want to be pushing back, improving the cure rate with their diseases . . ." (Interviewee 1)

### **Physicians' Perceptions of Patients' Age and Life Circumstances**

Interviewees unanimously rejected chronological age as a decision criteria and pointed out that age, in the sense of biological age, as a relevant clinical criterion should not be equated with chronological age. However, a number of interviewees reflected on the possible role of age as a nonmedical factor. In

this context, age-associated attitudes or life circumstances were perceived as influential nonmedical variables that influence decisions about the offering or limiting of cancer treatment. Physicians reported that they perceived older patients' as more accepting towards the limitation of cancer treatment than younger patients. Moreover, patients' life circumstances and especially family-related obligations, such as raising a child, were perceived as influential variables in favor of further aggressive treatment in advanced cancer.

"I think instinctively you feel that this is a young patient with a young family you need to make even more effort to try and help them live for a bit longer." (Interviewee 1)

"But I guess if I'm honest really, if you've got somebody who is bringing up their family and in their middle years and all those things, and maybe those things cross your mind more often than they would for somebody who's 85. And they ask more often. And they look for more things." (Interviewee 12)

The narratives of the physicians further suggest that, in some cases, the physician's own age and biography in relation to the patient's age and (perceived) life circumstances may also influence decisions about the offering or limiting of treatment in advanced cancer.

"I think I do, though, feel like that, especially if the patient's now younger than me. A bit, I feel, you know, he hasn't had his life." (Interviewee 1)

"I most recently had a young woman . . . with teenage daughters, the same age as my daughters, so there was a kind of sense of . . . it shouldn't influence, but you can picture the person the same as yourself." (Interviewee 12)

### **Strategies of Professional Decision Making in Situations of Scarce Evidence**

Several interviewees referred to the challenges of making decisions about offering or limiting cancer treatment based on the scarce evidence available.

"It's difficult to say that this will extend your life by a few weeks. It's very speculative, you know." (Interviewee 4)

In this context, the value of multiprofessional team discussions was emphasized in several interviews. In addition the function of gathering all available information, physicians viewed multiprofessional team discussions as providing good opportunities to exchange different views and opinions of the healthcare professionals dealing with current cases, and thereby to inform about any treatment decisions in this respect.

"We will sit down and discuss the patients on the ward with all the medical teams . . . And it allows the staff to discuss the extremes of opinion and meet at a medium level." (Interviewee 2)

In the light of the difficulties of applying current clinical research data to decisions about the provision or limitation of cancer treatment at the end of life, one further strategy to improve decision making mentioned in a number of interviews



was to build up a body of evidence within clinical services that can be applied to these decisions.

“So we’ve been doing the morbidity/mortality for just over a year and now we . . . start doing monthly reviews on post third-line chemo for breast, say, and sort of chemotherapy for pancreatic . . . to say whether or not there’s a benefit to the patients or whether or not we should stop doing it.” (Interviewee 11)

## DISCUSSION

This qualitative interview study provides insight into factors possibly relevant to medical oncologists’ decisions about the offering or limiting of cancer treatment in advanced disease. We focus in the following analysis on the medical and ethical implications of physicians’ framing of treatment approaches as “active treatment” or “palliative care,” as well as on the role of nonmedical factors relevant to physicians’ treatment decisions in advanced cancer and the suggested strategies for professional decision making in situations of scarce evidence.

### Framing of Different Treatment Approaches: Clinical and Ethical Implications

The physicians in our study distinguished “active treatment” from “palliative care” as different treatment approaches in the context of advanced cancer. Although similar distinctions have been reported in other studies [2, 21–23], our analysis provides a detailed account of important ethical and clinical implications of such distinctions. From an ethical perspective, the values and preferences of patients should not only be at the center of consideration in situations of palliative care but also in situations in which, from a professional point of view, there is a chance to change the course of the disease.

Although there often seems to be an implicit agreement between patient and physician regarding a disease-oriented focus in cases of curative treatment options, it is well established that physicians often misjudge patients’ preferences [5, 24, 25]. From a clinical perspective, the framing of “active treatment” and “palliative care” as mutually exclusive categories may be associated with the risk that supportive or palliative care measures may not gain enough attention in the context of active treatment. However, recent evidence indicates that, at least in some cancer entities, an early combination of active treatment and palliative care can lead to better clinical outcomes [26].

### Nonmedical Factors Relevant to Treatment Decisions in Advanced Cancer and Possible Strategies to Improve Professional Decision Making

The interviewees reported a number of nonmedical factors that influence decisions about the offering or limiting of cancer care. In this context, the physicians’ values and individual priorities regarding the goals of treatment (i.e., increasing length of life vs. a focus on quality of life), as well as perceptions associated with patients’ age and their life circumstances, are named as relevant factors. Due to the methodology of our study, it is not possible to state whether these factors actually influence clinical practice regarding the offering or limiting of cancer treatment in advanced disease. However, the findings provide plausible explanations for the findings of quantitative surveys, which have repeatedly

shown variation in end-of-life treatment that cannot be explained by differences in patients’ preferences [5, 13, 27–29].

Moreover, the results show similarities with the data gained by a qualitative study conducted in the Netherlands [2] and with parts of the findings of an earlier qualitative study conducted by the first and last author in Germany [18]. The comparative analysis of our studies conducted in Germany and with German oncologists indicates that, even in light of different health systems and philosophical traditions, the reflections of the physicians in both countries on the role of their personal values and their perception of the patients’ situation may be influential concerning treatment recommendations in advanced cancer. Against the background of the available body of knowledge gained by the studies cited in Germany, the Netherlands, and England, as well as anecdotal evidence [17], we suggest that the role of personal views and perceptions of oncologists on treatment decision making should be investigated in larger quantitative studies. Such research could generate more robust and generalizable data, which, in turn, would be a prerequisite to inform educational and policy interventions relevant to treatment decisions in advanced cancer.

In addition to the aforementioned qualitative research, the role of physicians’ health-related values in treatment decision making has been the subject of numerous conceptual studies [30, 31]. We argue that respect for patient autonomy requires clinicians to make explicit any value judgments underlying health care professionals’ recommendations. Moreover, transparency regarding the well-known scarce evidence available for treatment decision making in advanced cancer [17] may help at least those patients who wish to be involved in decision making to better grasp the decision at stake. In this context, it should be noted that a number of interviewees themselves suggested multiprofessional team discussions, as well as building up a body of evidence that can actually inform treatment decisions in the last phase of life as a means to improve professional decision making. This finding, which has been neither elicited in our earlier study with German oncologists [18] nor found in other relevant studies known to us, is important because it provides an angle from which interventions such as educational training or policies could be implemented in a way that could be acceptable by medical practitioners.

More concretely, we argue that an intervention that takes into account the scarcity of evidence and the subjective dimension of treatment recommendations in advanced cancer, on the other hand, could be linked to oncologists’ experiences and views. Such a link to oncologists’ perception and experiences seems to be important for the acceptance of any intervention that aims to improve treatment decision making in advanced cancer. The aforementioned strategy could be further bolstered by reference to the increasing evidence that clinical ethics support services provide an effective means to facilitate the deliberation of values related to treatment decision making in medicine [32, 33].

A number of methodical limitations must be taken into account when interpreting the findings of this study. First of all, the study is based on a small number of in-depth interviews with medical oncologists working in English NHS institutions, so the findings cannot be generalized. It is likely that the expe-

periences and views elicited in this study may not cover the whole range of experiences and views of medical oncologists. Secondly, it is possible that a selective memory and socially desirable answers may have influenced the narratives of the interviewees. Thirdly, this study focuses on the criteria and variables relevant to professionals' decisions or recommendations. These decisions cannot be equated with the actual treatment decisions in practice, which are determined by additional factors, such as patients' preference, patients' knowledge about the disease and treatment available, and further factors.

One strength of the study is that, in addition to the extensive experience of qualitative research in medical ethics amongst the study group, the interviewer has a clinical background in medical oncology and was able to appreciate the medical aspects presented in the physicians' narratives. At the same time, he could identify and explore relevant ethical issues, such as the nonmedical variables relevant to physicians' treatment decisions. A second strength of the methodical approach chosen lies within the function of qualitative research to differentiate findings, which had been presented as part of quantitative studies. A good example of this function of qualitative research is the account concerning the role of age in treatment decision making for advanced cancer, for which the qualitative method enabled the exploration of distinctions drawn by participants between chronological age and functional age, as well as age relative to the treating physician and age-related life stages and responsibilities.

## CONCLUSION

The findings of this qualitative study suggest that the framing of treatment approaches in the context of advanced cancer, as well as physicians' individual treatment recommendations with regard to the provision or limitation of treatment, are value laden. To make these values explicit is a prerequisite for ethically informed treatment decision making in advanced cancer. In addition, this study underlines that clinical research on the outcomes of different treatment strategies in advanced cancer is necessary to overcome the existent scarcity of data in this respect; the emphasis on values is not to detract from the importance of research evidence. Finally, clinical ethics research on how to make use of available clinical data and ethical concepts relevant to treatment decisions at the end of life is needed for ethical, evidence-based treatment decisions for advanced cancer.

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## AUTHOR CONTRIBUTIONS

**Conception and design:** Jan Schildmann, Jacinta Tan, Jochen Vollmann

**Provision of study material or patients:** Jan Schildmann, Jacinta Tan, Jochen Vollmann

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**Final approval of manuscript:** Jan Schildmann, Jacinta Tan, Sabine Salloch, Jochen Vollmann

## DISCLOSURES

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